

## **Track 1: Introduction**

### **[Narrator]**

Welcome to the *Cancer Survival Toolbox*<sup>®</sup>, an award-winning program brought to you by the National Coalition for Cancer Survivorship – NCCS for short. With a grant from the Centers for Disease Control and Prevention, NCCS created this special program focused on non-Hodgkin lymphoma. You can listen to this program alone, or use it with the original *Cancer Survival Toolbox*<sup>®</sup>. If you recently received your diagnosis, you may want to listen to the *Toolbox* programs on “Communicating” and “Finding Information”. “First Steps for the Newly Diagnosed” might also be relevant. As non-Hodgkin lymphoma is generally diagnosed in an older population, “Topics for Older Persons” may also be of interest. You can also refer to the resource booklet accompanying this CD.

There are two major types of lymphoma: Hodgkin and non-Hodgkin. Each has several different forms. Both are cancers of the lymphatic or immune system, but non-Hodgkin lymphoma is diagnosed eight times more frequently. There are many types of non-Hodgkin lymphoma. About 85% are a B cell type. Others are T-cell or NK. Lymphoma can be fast growing, which is called aggressive, or slow growing, which is called indolent. Some “fast growing” patients can be cured. Treatment can keep slow growing lymphomas in check for years. Treatment options vary with each type, so it’s important to know the exact type of lymphoma diagnosed.

Let’s listen to survivors talk about challenges they’ve faced.

### **[Voice #1]**

I had a lump in my groin for months. The doctor kept giving me antibiotics thinking it was an infection. It took forever to find out it wasn’t an infection and to figure out what I had.

### **[Voice #2]**

Since I was having bad night sweats and suddenly lost weight for no reason, the doctors immediately suspected lymphoma. They just had to be careful to figure out what kind it was so they could start me on the right treatment as soon as possible.

**[Voice #3]**

My lymphoma is slow growing. Rather than start with treatment right away, I have to wait. Waiting's hard.

**[Voice #4]**

My lymphoma keeps coming back, so I'm always anxious about what will happen next. My daughter found out about clinical trials. I want to talk to my doctor to see if one is right for me.

**[Voice #5]**

I think the uncertainty and treatments are harder on my family than me. Fortunately, we learned about support groups and educational programs for all of us. It helps to know there are resources for these tough times.

**[Voice #6]**

I'm still not sure what lymphoma is. They call it blood cancer, but then talk about it being in the lymph system. What is it and where is it?

**[Narrator]**

As you can see, lymphoma can be difficult to explain.

It's very important that the type of lymphoma be diagnosed accurately, as treatment options and outcomes vary with each type. Due to the large number of types of lymphoma, it's important a doctor specializing in lymphoma review your biopsy and other tests.

Let me explain why non-Hodgkin lymphoma is complex. We suggest you use the diagrams and graphics in this CD's companion booklet to better understand how lymphoma is diagnosed.

When we discuss lymphomas, we talk about the interplay between the immune and lymphatic systems. We stay healthy when all parts work together to control cells that shouldn't be in the body

and may cause disease. The immune system has white cells called lymphocytes that fight infection; the lymphatic system or network of vessels containing lymph fluid; and different organs like the spleen, thymus gland, tonsils, adenoids, and bone marrow where lymphocytes are made. By working together, these components contain or destroy invaders like viruses or bacteria. They also protect us from abnormal cells that transform into cancer cells inside our body.

Let's look at the lymphatic system. It's made of a transportation system, a filter system, and a search and destroy system.

- The TRANSPORTATION system is a network of lymph vessels similar to blood vessels that transport lymph fluid containing lymphocytes.
- The FILTER system is a series of lymph nodes and tissues or organs like the spleen that filter out foreign material or cells that threaten our health.
- The SEARCH & DESTROY system is composed of lymphocytes known as B and T cells. B cells produce antibodies that attack and digest viruses and bacteria. T cells act as backup to B cells, and destroy cancerous cells.

If an error occurs during lymphocyte production, and the abnormal cells are in the lymph system, lymphoma can develop. It takes many steps to develop lymphatic cells, these cells have multiple parts, and these cells can develop in different parts of the lymphatic system. These factors play a role in what type of lymphoma is diagnosed. Ask your healthcare team to draw diagrams and explain what type of lymphoma you have, so you can understand your disease better.

Because non-Hodgkin lymphoma has many different forms, some survivors need only one course of treatment, others need multiple courses over years, some need to change their treatment, and some need stem cell transplants.

Before we move on, let's discuss this term "cancer survivor." We feel everyone diagnosed with cancer is a survivor – from the moment of diagnosis until the day we die. You can also use the term "patient." We use "cancer survivor" to mean anyone dealing with lymphoma.

Let's hear from Maria.

**[Maria]**

I'll probably require treatment for the rest of my life. Anyone faced with a chronic illness like lymphoma must not only manage everyday activities, but also coordinate doctor visits, prescription refills, insurance claims, and caretaking responsibilities.

**[Narrator]**

Lymphoma is a serious disease; treatment for Maria may be needed throughout her life. Maria's a long-term cancer survivor. She'll always have lymphoma, yet she lives with periods of remission when the disease is inactive. Some types of lymphoma can be cured. Others can be treated throughout a person's life. It's important to note there are many resources to help you and your loved ones.